Disability Visibility Podcast

Episode 23: Paratransit

Guests: Jessica Moye and Denise DiNoto

Host: Alice Wong

Transcript by Cheryl Green

For more information: https://disabilityvisibilityproject.com/podcast/

Introduction

[radio static, voices singing with hip-hop beat]

LATEEF MCLEOD: This is the Disability Visibility Podcast with your host, Alice Wong.

ALICE: Hey hey hey! Welcome to the Disability Visibility Podcast, conversations on disability politics, culture, and media. I'm your host, Alice Wong. Our last episode was about public transit, and today we're exploring paratransit with my guests Jess Moye and Denise DiNoto.

There are some people with disabilities and older adults who, for various reasons, cannot take buses or trains with fixed routes. Paratransit services are offered alongside fixed-route public transportation, and they usually provide door-to-door services in a taxi, van, or a bus. Sounds great, right? Well...kinda sorta.

My guests Jess and Denise use paratransit services, and they'll share what it's like in comparison to public transit or rideshare. They'll also describe the amount of labor they expend as riders and how those services impact their ability to work and participate in social life.

Are you ready? Away we go! [electronic beeping]

ELECTRONIC VOICE: 5, 4, 3, 2, 1!

ALICE: Jessica and Denise, I am so glad to have you both on the podcast today. Welcome!

JESSICA and DENISE: Thanks so much!

ALICE: So, why don't I have you both, I guess, introduce yourselves and say a little bit about who you are and where you're located and anything you'd like to share, your background. Jessica, do you wanna go first?

JESSICA: Yeah, sure. No problem. My name is Jessica Moye, and I am a Afro-Latinx disabled activist who lives in Queens, New York. I identify as non-binary, and I am a lover of cupcakes.

ALICE: Great! How about you, Denise?

DENISE: Sure. So, my name is Denise DiNoto. And I am also in New York, but I'm just outside of Albany, New York. And I am also disabled. I consider myself more of an advocate, but this year, I'm definitely tipping more towards activism. And I am a lover of cookies. Since Jessica opened that door, I can say that.

ALICE: Well, I'm a lover of cupcakes, cookies, and donuts. So, I think we are kindred spirits.

JESSICA: Indeed, indeed.

What paratransit is, how it differs from mass transit, and barriers around scheduling

ALICE: So, I wanna ask both of you this question. For people who don't know much about paratransit, how would you describe it to them, and how does it differ from mass transit?

DENISE: I can start, and Jessica, you can feel free to hop in.

JESSICA: Right, sure.

DENISE: So, fixed transit is established on a route system. Cities and municipalities that operate fixed-transit systems, usually bus lines, have bus routes that are established, and usually they're on a schedule. And if you wanna go somewhere, you figure out where you're going on your schedule, and you hop on the bus stop that's on the corner of 1st and River. And you go on the route that takes you to Pine and South Main or wherever it is that you are trying to get to.

Paratransit is different in that most of the systems are what's called shared ride on demand. So, there's not a fixed route. If you're trying to go somewhere, it's a door-to-door service that picks you up from home—usually, home has to be within a certain amount of miles from a fixed bus route—but it provides you with service from home to wherever it is you're going to go.

JESSICA: Right. And one of my main gripes with it is that you have to schedule rides in advance. Whereas with mass transit, you can simply go to a bus stop or a subway stop and catch something from there. With paratransit, you have to call or use an online portal to schedule trips at least 48 hours in advance. And many times, as well, you have to do so before a certain time. Like, the latest you can, or you can't schedule paratransit here after 5:00.

DENISE: Right. Ours is 4:00.

ALICE: What?! Oh, my goodness.

JESSICA: Oh, wow. And I thought ours was bad. Wow.

ALICE: So, there's no nightlife, right?

DENISE: Well, you can have a nightlife; you just have to plan it before 4:00 pm the day before.

[mellow, chiming music]

DENISE: So, for example, I live on a bus route that does not begin service on Saturday mornings until 7:44. So, I can't schedule my first pickup on Saturday mornings until 7:44 am or after.

JESSICA: Oh, that's— Wow! I haven't experienced anything like that. But that's really— My issue with paratransit here is more so like the parameters with which you can go. Like, you can only go throughout the five boroughs and no more, I think it is, than two miles into certain counties. And you have to, for example, if I wanted to go into Long Island, I would have to stop at a transfer point at a mall in Valley Stream and then transfer to the Long Island version of paratransit, which is quite annoying.

ALICE: And it's not that easy either, is it?

JESSICA: No, it's not. I've actually never done that transfer because I'm afraid of being stranded.

ALICE: And also, you have to be, I guess, a client of the other paratransit.

JESSICA: Yeah, you have to, even if you're not a client, you have to call them and let them know so they can transfer over your profile, so they know what to expect to get you. And then you can't do that regularly. If you wanna do it regularly, you have to apply and become a client of the other sister paratransit company. It's not something that picks up automatically.

DENISE: Right. But paratransit is reciprocal, I mean, in most places. If I went to New York City and wanted to use their paratransit system, I could notify them. Because I'm a rider of my local paratransit system, I could use their system.

JESSICA: Right. You can do that, but you still have to notify them.

DENISE: Right. You still have to schedule, and you have to go through everything well in advance.

ALICE: Yeah. And in advance is the point of emphasis, right?

JESSICA: Yeah.

ALICE: Because this is a main difference that a lot of disabled riders who use paratransit just have to really plan out their schedule way in advance compared to other folks who can use other forms of transportation.

DENISE: Right. So, for instance, this week, because I work in an office, I work full time. And my office is open till 5:00. At 4:20 on Wednesday, a meeting was scheduled for 11:30 on Thursday morning. But I'd already made my arrangements for paratransit, and I wasn't going to be picked up to go to the office until 12:00. So, I had to find someone. Thankfully, I have my own van that somebody else could drive me in. But I had to make arrangements with a personal assistant who could come and drive me in my van to the office so I could be there for the meeting. Because the meeting was scheduled after I could make reservations for paratransit.

ALICE: Yeah, and life happens, right? It's like, there's a lot of things that happen to people the day of, emergencies or errands. And that's really difficult to accommodate. Do you have any stories to share, Jessica, about that?

JESSICA: Yeah! Those things are really difficult to accommodate. For example, New York City paratransit, they only allow you, like if you're at a doctor's appointment, and you're running late, you can call an hour before your pickup time to go home and reschedule another ride or ask to be put on a hold while they find you another ride or call them when you're done, right? But you can't do that under any other occasion. So, if I were at a wedding that went over a certain time— Or like recently, for example, I went to a concert, and I literally had to email the venue and was like, "Hey, what time is the show gonna be over? Because I need to coordinate a ride." And my thing is like, I do live near accessible bus stations and train stations, but when I take the train, my commute is just as long as it is with paratransit. So, it really, you know, both of those options are just about the same for me. One is not more or less feasible than the other, you

know? If I go to Manhattan, I'm commuting and hour and a half to two hours either way, no matter which way I go.

DENISE: And we don't have a train option. So, it's either the bus and paratransit, or I'm taking a taxi. And we have only a couple of accessible cabs in the area. Or I don't even know if we have an accessible Uber vehicle or anything.

The economics of using paratransit

JESSICA: Right. And I've done accessible cabs a couple times as well. And what I don't like about it through paratransit is it takes all of three months for you to get that reimbursement. It's like I'll spend $80 on a cab to come home from the City, and I gotta wait three months to get it back? That's a lot of money and a long time to wait for a lot of money.

ALICE: And not all people with disabilities can wait on that, and that's really tough. 'Cause I think economic issues are a real reason why so many disabled folks rely on paratransit, because it's one of the more affordable ways to get around.

DENISE: Absolutely. I mean, I can take a ride on paratransit from my house to where I go to exercise three times a week, and it's $5/trip. 'Cause it's $2.50 each way. If I took a cab, it would be an $80 cab ride one direction.

JESSICA: Yeah. Yeah, definitely. But one thing I notice as well, for me, for example, because I'm a wheelchair user, I have a disability let's say. 'Cause I think it goes for most people with disabilities: When I get on like a city bus, New York City bus, I can pay half the fare, which is I think something like $1.35. Whereas, with paratransit, I have to pay a full $2.75 because it's owned by the MTA. So, whatever the standard bus or train fare is, that's what the paratransit fare is. So, I don't understand how, if I go to the local strip mall where I go to get waxed, or I'll go shopping or wherever, it's cheaper for me to take the bus than it is for me to take paratransit.

ALICE: Yeah, that is curious.

JESSICA: Yeah.

[jazzy electronica]

Making a reservation and waiting for pickups and drop-offs

ALICE: Can you both tell me a little more about the process of making a reservation and the amount of time you have to wait when they pick or drop you off?

DENISE: So, I remember the days of paratransit where you would get on the bus at 6:00 in the morning, and you would ride around for three hours before you go to your destination at 9:00 in the morning. And then you would ride around for three hours before you got home. So now, most of my ride times are only about an hour to an hour and a half. So, I've seen vast improvement in that. 'Cause I'm still wasting time, but I'm not wasting as much time as I was. But like Jessica alluded to, I think the window that they're allowed to be late before you're allowed to call them and check on where your ride is, is frustrating.

What happens when you make a reservation, you can request a reservation either online or on the phone. And I do everything online so that I have a record of when I've put my requests in and when they've told me they've received it. But you put your reservation in, and they can schedule you for up to an hour before or an hour after your pickup window.

JESSICA: Right.

DENISE: And when they come to get you, you'll confirm your pickup time, and they can be up to 25 minutes late and still be considered on time. So, like for instance this morning, my pickup time when I called and confirmed was 9:35, and so I couldn't call them to ask where my ride was until 10:00. Because they were still on time until 10:00, and they didn't show up until 10:06. But I had to wait the half an hour, basically, until they got there.

ALICE: Right. And that just seems so ridiculous because how does anyone really ever estimate getting to somewhere on time? Because clearly, if the ride is out of your control in terms of when they pick you up and how long their allowed to be late, yeah, that eats up a lot of your own time that you could be doing a lot of other things. So, what is that like in terms of just having to deal with the extra labor but also the loss of your own personal time?

JESSICA: It's very frustrating. Our window here is 30 minutes. And while they're not as diligent as they used to be about it before, I'll usually wait 15 before I call and ask where my ride is. But it's still the same thing: A lot of times when I call, they'll be like, "Ma'am, your driver is still within his window." And the reason why this window is also annoying is because they are allowed to wait no more than 5-8 minutes for us. So, if you're anywhere between 5-8 minutes late, or after that, let's say, they can leave you. And that's the really frustrating part. So, we have to wait 30 minutes for you, but you only have to wait 5-8 minutes for us. And that's not fair.

A lot of times, when you make appointments— For example, if I have to be somewhere 1:00, I'll usually say 12:00 because they're not great at getting you there on time. Most of my commutes are an hour and a half, two hours both ways. And like Denise mentioned earlier, I do remember the days of being on Access-A-Ride for three and four hours. But I can tell you that it hasn't really improved much. They do have stipulations in place where you're not supposed to be on a bus for more than two hours at a time. But when I tell you that most times, my commute going into Manhattan is just about that two hours, and coming back, yeah. They really push it.

ALICE: And that's a whole day.

JESSICA: Yeah, that's a whole day. It's like four hours. And I'm not working right now, and that's one of the reasons why, is because I have trouble finding work within my area. Because the thing is, I don't want my commute to outweigh my work day. You know what I mean? I don't wanna spend my whole work day commuting to work or commuting home. It makes no sense.

ALICE: Well, it's like having two jobs, right?

JESSICA: Yeah, yeah.

[mellow guitar music]

JESSICA: And like, it's just one of those, to have to waste your time that way and your spoons or your energy and everything is very frustrating a lot of the time.

DENISE: The other night, I was on my way home, and we stopped to pick somebody else up. And the driver was going to drive right past my house to go another two miles to drop this person off, but I had already been on the bus for an hour and 15 minutes. And so, I said, "Wait a minute. Can't you just stop and drop me off before you go and drop her off and then pick somebody else up and then come back and drop me off?" Literally, we were driving right by my street at night. And so, she, the driver did that. She called dispatch and said, "I'm just gonna

drop Denise off first if that's OK." But otherwise, I would've been on the bus another half an hour.

Energy, foresight, planning, and labor it takes to use paratransit

ALICE: Again, a lot of people who don't know much about paratransit or know much about the real realities of what it's like to be disabled and to get around, there's so much invisible and emotional labor that is expected by us just to get out there. And I guess, would you like to share any examples of just, or anything about the amount of energy and foresight and work it takes for you both just to get all your needs taken care of? You know, I think so many people—even people with disabilities who don't need to use paratransit or don't need to use mass transit—don't realize all the work that it takes.

DENISE: Oh, so, I'm one of those people that was disabled but didn't use paratransit for a while because I had my own vehicle. And I broke my leg last year, and I am not able to drive independently right now while I'm waiting for a new van. But I drove all the time when I was working for 20 years and didn't have to rely on paratransit for my employment. And I was blissfully unaware. I mean, I knew about some of the hassles, but I really didn't understand the impact of how it really hits. Each and every day, they have to make those plans ahead of time because if you don't make your reservation by 4:00 pm, you don't go anywhere the next day. And if your employer, especially, is counting on you to be somewhere the next day, and you aren't able to make your reservations to be there, now you're putting your employment in jeopardy perhaps. Unless you have a really understanding employer who's going to understand the system. But it's also stressful because then you have to think, well, how else could I get there? What are my other alternatives for transportation? Is there another way that I could make this work?

And then, what if I'm late coming home, and my personal assistant is waiting for me at home to help me, and maybe they have to go to another client or consumer after you? And so, now you're gonna make them late because you're late getting home. And you have a certain amount of needs that have to be met. So, is it worth trying to find a different personal assistant to come at last minute, or are you better off just trying to rush through your tasks so that your personal assistant can get to their next job, hopefully on time?

It's a constant, everyday thought. There's not a day that goes by that I don't think about transportation. Whereas, when I had my own van, and I was driving, I really never thought about it.

[ethereal ambient music]

ALICE: Thank you for sharing that, Denise. I really appreciate it.

JESSICA: I definitely agree. And going back to what Denise was saying before, I actually became a subscriber of paratransit when I was 11. My mom had applied for me, and I don't think we used it much back then. We maybe used it like once or twice, and now I see why. Because when I turned 18, and I cultivated my own social life, that was my way of getting around. And to this day, it's still difficult. You know, it's very difficult to explain to non-disabled people or other disabled people that don't have these services that you have to plan your social life ahead. It kind of puts a damper on things. People aren't always as flexible. Or when there's gonna be a family event and things like that, and they wanna go to a venue that's just outside of the borough or something like that. And you have to find out if they go there and all this stuff. It's very time-consuming, it's very daunting, and it's very just really frustrating.

DENISE: It's challenging if your interactions with your family have mostly been spontaneous, and you know, "Oh, it's Friday at 3:00. What do you think? We should go to happy hour this evening." You know, my sister and a group of friends and I used to do that often, and I could never do that now. I mean, last week Friday, we went out together after an event, and on Thursday at 1:00, I'm saying to them, "Remember: I need to make a reservation by 4:00. So, where are we gonna go tomorrow night?"

ALICE: Yep.

JESSICA: Yes. Definitely. I can definitely relate to that. I mean, honestly, even for me personally—I don't know you, Denise—but a lot of times, it deters me from dating. Because I feel like that's a logistical piece of my life that so few people would want to accommodate. Because a lot of what dating is, is supposed to be spontaneous and fun and all that kind of stuff.

DENISE: This is just one of the many reasons I'm not dating right now, but I completely understand that, yeah.

ALICE: Yes, dating. And it's also just another thing is that paratransit, people think, oh, it's for like medical appointments, and it's for errands. It's for these important tasks. But it's also just about having a life.

DENISE: Right.

JESSICA: Yeah.

ALICE: And you know, people are entitled to party, to go out to bars, to date. But people don't think about all these things, all these complications that happen when you happen to be disabled and happen to need paratransit as your source of transportation.

DENISE: Well, I will say in defense of paratransit, it is the best designated driver I've ever had. I will say that about it. Because I can go out with my friends, and I can have a couple cocktails. And I never have to worry about how I'm getting home because I know I've always got a sober ride home. So, that is a good thing.

JESSICA: [chuckles]

ALICE: That is the one good thing, maybe.

JESSICA: But that's about the only thing. And even sometimes, as Denise was saying, I now do most of my reservations online. But back when I was in my 20s, and I was going out a little more often and stuff like that, I would call to make reservations. And one of the questions they always asked is, "What type of place is this?" And I would say, "Well, it's a bar," or "It's a restaurant," or "It's a tattoo shop" or whatever it was. And they would have this condescending tone with me as if to say, "Oh, wow. That's where you're going?"

[upbeat piano music]

ALICE: Yeah, it feels very, you know, this whole medicalization of paratransit, right? Like, you have to prove your disability, and somehow you have to prove how needy you are. And they can make all these judgments about your trips and how you wanna use your trips, which is just so infantilizing, I think.

Recommendations for improving paratransit

So, just to wrap up: I wanna ask both of you—because we talked about some of the problems, some of the barriers you both face—what are some of your recommendations for improvements in the way they help you, whether dispatch, whether it's drivers, whether it's paratransit policies? What kind of suggestions would you like to make?

DENISE: Because I'm a tech person, and I use my phone for everything, and I have access to technology, I would love a text alert system that would let a rider know when their bus is actually close to being there so that I don't have to waste as much time waiting. For example, if it's the end of the day, and I'm coming home from work, and I have a scheduled pickup for 6:00 pm, but the bus is not actually gonna be there until 6:20 or 6:25, well, there's no reason I can't keep working until then. The only reason I shut down is because I can only be five minutes late, or else they're gonna leave without me. But if they know that they're not gonna get there, why can't they send a text alert system? The buses have GPS monitors on them. They're able to track, in dispatch, where the buses are. Why can't we have some sort of notification? And there's been talk about a potential notification system, but it hasn't happened yet. But I would be really hopeful that that might be something that we can get locally. It should be.

ALICE: Especially if it's all automated, it should be very simple. How about you, Jessica?

JESSICA: One of the things my paratransit system is doing is that we actually do have a notification system. You get an automated call telling you how many minutes your ride is away. It's usually not accurate, but at least it lets you know that your pickup time is approaching. And then in addition, you get an email that tells you the vehicle number and the carrier coming to pick you up. So, that's good.

But just to draw on what Denise said, I would love some sort of app that I could use on my phone that would actually track the vehicle and make reservations and have text alerts as well. Because those are a lot easier to see, and they don't eat up your— I mean, most of us have unlimited plans these days; I do myself. But I'm thinking about the person that maybe doesn't. And checking for an email notification is gonna eat up their data.

ALICE: These are great examples, and they're really great suggestions. I really hope that if anybody who's listening will take your feedback seriously. Any other, I guess, final comments?

JESSICA: A lot of times, the thing I struggle with is should I use the bathroom before they come or while I'm waiting? Because what if they come while I'm waiting, and I'm in the bathroom, and they don't know that I'm in the bathroom? So, I literally have called and say, "Hey, how late is the driver gonna be? Do I have time to use the bathroom?" Like, I literally have to say that. For someone like me, it doesn't take me two minutes. It takes me about 15.

ALICE: It takes me 20. It takes me 20.

JESSICA: Yeah, so you know, having to call and say, "Can I at least use the bathroom?" Because another thing, let me just touch on this real quick, is that they do have the GPSes on the buses. But I learned this from a driver years ago: They can be within 75 yards of your destination, say that they're there, be marked as there, and if they don't see you, they can just drive off. I've had rides not show up. I've been left. I've literally watched vehicles drive away from me when I was literally flagging them down.

ALICE: Oh, my goodness. Wow.

Wrap-up

Well, thank you both so much for talking with me today.

DENISE: Oh, this has been a lot of fun.

ALICE: I really appreciate it.

JESSICA: Yeah, this was great. Thank you.

[hip hop]

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Thanks for listening, and see you on the Internets! Byeee!!

♪ lets dance
get as low as you would if you were in sweat pants
How far will they go?
Oh, yeah yeah ♪